

Using art for public engagement: reflections on the Dementia and Imagination project

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Introduction

Dementia is perhaps the greatest challenge to healthcare in the future. It is reported that 46.8 million people have dementia worldwide. This is predicted to increase to 74.7 million in 2030 and 131.5 million in 2050 (Alzheimer's Disease International, 2016). In the UK it is estimated that 850 000 people are currently living with dementia, with numbers predicted to rise to over 1 million in 2025 (Alzheimer's Society, 2016a). Apart from those diagnosed there are many more individuals living with symptoms of the condition and often inadequate support. There is no cure for dementia and pharmacological treatments e.g. anti-psychotics are limited in effectiveness. For this reason there is growing interest in the field of psychosocial care that aims to improve health and wellbeing throughout the journey of dementia, enabling people to 'live well' with the condition. There is also a growing acceptance of the important role creative activities can play in the mental and physical health of communities, including improving health and wellbeing for those with dementia (see e.g. Creative Health, 2017; Postlethwaite, 2019). The 'Dementia and Imagination' (D&I) project responded to this agenda and over three years developed, implemented, and evaluated a visual arts activity in care homes, in the community and in clinical settings, in diverse parts of the UK: North Wales, Derbyshire and Newcastle and the North East. Amongst the wider aims of the project, D&I focussed upon "improve[ing] the quality of life and community connectedness of people living with dementia" as well as to "challenge and change the public perception of dementia" (Newman et al., 2016).

There is public confusion about the nature of dementia and its prognosis e.g. using the term dementia and Alzheimer's interchangeably, and much fear associated with

the condition. A survey by the Alzheimer's Society reported that two thirds (62%) of respondents felt that their life would be over if they were diagnosed with dementia. The same survey indicated that: *'Fifty eight percent thought they would personally struggle to join in conversations post-diagnosis and 49% worried people would think they were mad'* (Alzheimer's Society, 2016b).

Dementia is defined as a neurodegenerative disorder characterised by a range of symptoms yet the severest manifestations of the condition are commonly presented. Cinematic portrayals often foreground the 'tragedy' of the condition (Alzheimer's Europe, 2013). As Zeilig (2013) suggests, dementia is often equated with *'a complex, unknowable world of doom, ageing, and a fate worse than death'*. The condition has also been connected with negative tropes that represent people living with dementia as the 'living dead' (Behuniak, 2011), a narrative that dementia charities and campaigners have been striving to overturn. Metaphors related to warfare are commonly used e.g. the ex-Prime Minister and now President of Alzheimer's Research UK David Cameron stated: *'We've got to treat this like the national crisis it is. We need an all-out fight back against this disease, one that cuts across society.'* (Prime Minister's Office, 2012). Such language positions people with the condition as 'victims'. Media reports typically focus upon the terminal phase of dementia rather than the entire trajectory of the condition, the burden on families, and often feature the voices of others speaking for people with the condition, rather than people living with dementia themselves (Van Gorp & Vercruysse, 2012).

Public engagement

From a Higher Education perspective, scholars are expected to maximise the impact of funding investment by creating impact outside of the academy e.g. using research findings to facilitate societal, economic, political or legislative change. It has been stated that *'public engagement is also the principal mechanism for not only evidencing but maximizing the potential impact(s) of research'* (Watermeyer, 2012: 117). This is part of a longer-term effort to connect research with the concerns of those who are being researched, but also to ensure that scholarly activity becomes embedded in practice, having been effectively communicated outside of academia. However, concerns have been raised relating to the *'abstract, emotive or cognitive qualifiers [that] seem difficult to translate into the measures or metrics of assessment'* (Watermeyer, 2012: 119) that are a requirement for measuring research impact in the evolving Research Excellence Framework (REF). This is framed within an understanding of impactful research that is able to demonstrate 'reach' and 'significance' of activities (Higher Education Funding Council England, 2015). Exhibitions and sharing events may demonstrate this 'reach' via societal impact, by informing or influencing public opinion (see AHRC, 2007).

This paper focuses on how creative activities were used to raise awareness of dementia and the D&I research and the impacts of this on audiences, using two activities to illustrate. Activities included placing artwork at festivals, in art galleries, in shops and other public spaces, enabling a wide range of people i.e. in different geographical areas, and reaching a variety of audiences, to view work made by research participants (people living with dementia) and by artists responding to the research.

Aesthetic Outputs

D&I, as a visual arts research study, has provided a host of visual materials to share: from art work created by participants during the art groups, to a number of creative workshops and installations. These were used to raise awareness of the study and of dementia more generally. As part of the research, three artists were each employed to create artwork in response to the study, acting as observers to the research process. Each artist was paired with one of the sites where research activity was conducted.

The interesting artwork produced by study participants was an unexpected outcome from the D&I project, see Figure 1. Although the project focused on the process of making rather than specifically producing art, a number of aesthetically pleasing and well-constructed pieces were produced. It was recognised that these had potential to create impact so they were included in a number of activities discussed below. Another project taking artwork made by people living with mental illness into a community setting demonstrated that it created a safe space for discussion about mental health and elicited empathy with artists (Tischler, 2017).

[insert Figure 1 about here]

D&I: public engagement activities

No. 3 Muddle St, The Green Man festival. Carol Hanson was one of the 3 ‘research artists’ attached to D&I. She worked closely with the team from North Wales, where many of the participants were in the earlier stages of dementia. Hanson’s artistic practice is distinctive in style, featuring illustration and sometimes animation, at its core. For D&I, Hanson created a number of accessible installations in public spaces, developing

and honing her research, experiences, and creative response to the project.

One of Hanson's first observations as part of the research, was the unexpected level of humour and laughter in the art group sessions. This feature became a strong element in her work, as well as embedding creatively within her practice the comments and reflections made by the participants, and even some of their art.

In 2015 and again in 2016, D&I took Hanson's installations to several events including the Green Man festival as a way of engaging the public in conversations around art and dementia. Einstein's Garden is a well-established feature at the festival, offering research, science and innovation activities that offer the public interactive opportunities. Hanson's work took the form of a 'cartoon car' and a 'living room', both belonging to an imagined couple, Doris and Ivor, inspired by research participants living with dementia. In both instances, the installations provided a way to utilise art to communicate and share the research with a wider audience.

During the event in 2016, members of the research team accompanied artist Hanson in staffing the installation at the festival. It recreated cartoon-couple Doris and Ivor's living room, within a 'gazebo-sized' pop up tent, see Figure 2.

Festival attendees could enter the tent to see Doris and Ivor's home brought to life. The installation itself was filled with elements linked to research such as cushions on two armchairs printed with art work that had been made by the participants. Another example saw a 'maze-like' wallpaper fill the back wall, reflecting the deterioration of the brain in dementia, based on Hanson's research related to the project.

[insert Figure 2 about here]

In order to involve the public, the installation included interactive games: a 'spot

the difference’ on two cuckoo clocks, printed on the wall, and a memory test involving a tray of objects, imitating 'brain-training' techniques that are used to try and stave off memory problems. As a way of documenting the impact of the installation, attendees left responses to the work on post-it notes in the form of memories, which were stuck to the ‘wall’ of Doris and Ivor’s living room. In total, 130 memories were collected over the course of the festival. A ‘comment curtain’ also provided a space for people to contribute any thoughts they wished to share about the installation and research. More than 800 people entered the installation, over the four-day festival, many of whom spoke at length with a member of the team about the research.

‘The Imagination Café’. During 2017-2018, The Imagination Café visited Nottingham, Llandudno, London and Edinburgh. The pop-up installation showcased art made by research participants living with dementia, providing the public with a welcoming, immersive café environment where they could explore creative activities, and find out more about dementia and the D&I project, see Figure 3. A range of activities, specially designed for people with dementia focussing on music, storytelling, drama and art activities were offered. An afternoon tea menu specially designed for people with dementia was provided by Nourish by Jane Clarke, plus advice and information stalls were led by Dementia UK and the Alzheimer’s Society staff.

[add Figure 3 about here]

Around 400 people visited the café over two days in Nottingham, 200 over 4 days in Llandudno, 500 during 5 days in London, and 300 over 4 days in Edinburgh. One interesting observation was that many came to the event without a particular interest in dementia. For example, in Nottingham, at least 15 people who identified as homeless

attended, 8 people who said that they were asylum seekers, and 2 adults with learning difficulties, the latter of whom attended for at least 3 hours on both days. In London and Edinburgh many tourists from outside the UK visited.

The impact of the public engagement events

Although the public engagement events were not part of formal research, ad-hoc feedback was sought for each. Fifty visitors to 'No 3 Muddle St' suggested that this type of approach was effective in engaging the public across all age groups. Writing on the 'comment curtain' one stated: *'I find the whole thing a wonderful invitation'*, whilst another commented: *'like being inside a cartoon, very clever'*. Beyond its visual appearance, others commented on the value of the research: *'really interesting and so important to use art in such a beneficial way!'* whilst another noted: *'I love the double edge irony of the chairs that speak of residential homes – but offer a creative alternative'*, which draws upon particular features of the work Hanson created.

Visitors to the 'Imagination Café' events were invited to leave feedback via visitor books and paper-based forms. Some commented on how welcoming the space was and expressed gratitude for the access to specialist advice that can be difficult to obtain via normal health and social care channels. The impact of the artwork made by people with dementia was noted. This included: *'inspiring artwork'*; *'dementia does not have to be a barrier to achievement'*; *'an amazing gallery with a great representation of their (people with dementia) capabilities, very touching and brilliant work'*; *'these works of art are a reminder that difficulties we may face and weaknesses we may have can be overcome'*, *'I can't believe I walked into such a positive and inspiring space on my first*

day in London'.

Reflections

Public engagement within research offers opportunities to engage with both specialised and general audiences. This can be particularly helpful to strategically influence and effect change within a number of areas crucial for research; in this case by providing a public forum and space for 'open discussion' (Alzheimer's Disease International, 2011: 9) that allows for a challenging of negative attitudes towards dementia. In this way, research can address key issues and concerns, by creating links between researchers, collaborators, and the wider public. In the case of dementia, where negative stereotyping persists, creative dissemination provides an opportunity for accurate information to be reported in engaging ways that can help to create dialogue, change public perceptions and to create a more hopeful perspective for care.

Whilst the D&I research team were largely positive about working with artists and creative outputs, it should be acknowledged that this type of collaboration can involve researchers' relinquishing control and may mean that the study findings are neglected or overshadowed by creative outputs (Bartlett, 2015). Watermeyer and Chubb (2018) refer to the liminal spaces that public engagement activities create which may facilitate potential vulnerabilities for academics when unbounded from more structured forms of methodologies and evidence. The activities were not systematically evaluated and future similar work might consider how its value and impact is measured in light of growing interest in public engagement e.g. within the Research Excellence Framework.

Conclusion

Creative approaches to dissemination can make research materials accessible, relevant, and engaging. This project demonstrated that creative activities and artistic outputs can generate interest in a topic, even one as emotive and potentially distressing as dementia. For the researchers and artists involved, there was reciprocity expressed and in most cases, individuals involved have gone on to work on other interdisciplinary research and scholarship involving collaboration between scientists and artists.

For the D&I project, utilising art both within the research and as a means of communication, encouraged people to engage visually and interactively with the project. The work often does not immediately invite associations with dementia which may be negative and might deter people from approaching or engaging with the creative materials. This careful approach, means that people's first associations are often joyful and curious, providing a comfortable space to broach a more serious conversation and to potentially challenge attitudes. This is because the artistic outputs discussed above visually present an image that is synonymous with the emerging message: that people can live well with dementia, with visual art activities being one modality that promotes this.

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[removed for blind review]

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